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F O R E W O R D

Between 1974 and 1977, Derek Thomas, Alan Kendall and Hugh Firth had the opportunity to visit the Eastern Nebraska Community Office of Retardation. Like so many other visitors, they were enormously impressed by the commitment of ENCOR and its workers to building a comprehensive community service for all children and adults from its region who are mentally handicapped, including all those still in Beatrice State Institution. The dedication and enthusiasm of ENCOR's workers and the agency's remarkable achievements since it was set up in 1970 are what this report is about.

One of the hallmarks of ENCOR is that it does not stand still. Its self-critical creativity, its openness to new ideas, are surely essential elements in its success. They are also some of the elements which most strongly challenge those of us concerned with services to mentally handicapped people in Britain, content as we seem to be to jog along, patching up our services rather than committing ourselves to any radically new direction or belief in the value of mentally handicapped people.

For this reason, we have tried to show in this report not just how ENCOR is today, but how it has arrived there. Derek Thomas visited ENCOR in 1974, with the help of a grant from the King's Fund Centre, and wrote the bulk of the report. Alan Kendall added his own impressions of the service from visits in 1975 and 1977. Finally, Hugh Firth undertook the task of bringing the material up to date as far as June 1977.

In an ideal world, all those concerned with planning and running services for mentally handicapped people would be able to go to Nebraska and see for themselves how ENCOR has changed since then - for there will almost certainly be some new initiatives towards the goal of enabling all mentally handicapped people to live as normally as they can in their own home community. It is hard to convey on paper the enthusiasm, determination and commitment which ENCOR workers, parents and friends bring to their task. CMH hopes that something of this comes across to readers and that they too begin to believe that if you want to build something badly enough, it will get built.

## EASTERN NEBRASKA COMMUNITY OFFICE OF RETARDATION (ENCOR) IN 1977

Population of five-county region served by ENCOR	569,000
ENCOR clients, 1976/7	891
active, July 1977	773
ENCOR staff, July 1977: total	414
part-time	43
full-time	371
People who have returned to ENCOR region from Beatrice State institution since 1970	259
People from ENCOR region still in Beatrice State institution	290
People waiting for admission to Beatrice State institution, 1968	42
1977	0
<u>Educational and Vocational Services</u>	
ENCOR pre-school programmes, June 1977	9
Children served in these	60
Home training (0-3)	11
School age programme, June 1977	1
Children in this	5
Children moved into ordinary schools, 1976/7	57
Children in integrated pre-schools, 1976/7	98
ENCOR industrial training centres, June 1977	4
Clients served in these	217
ENCOR advanced training centre, June 1977	1
Clients served in this	42
ENCOR work stations in industry, June 1977	5
Clients working in these	73
Clients who moved into competitive employment, 1976	76
from ITCs	31
from community	45
<u>Residential Accommodation for children</u>	
Training residences, July 1977	7
Children living in these	31
Developmental Maximation Unit, July 1977	1
Children living in this	6
Alternative Living Units, July 1977	32
Children living in these	53
<u>Residential Accommodation for adults</u>	
Training residences, July 1977	7
Clients living in these	31
Alternative living units, July 1977	64
Clients living in these	110
<u>New clients given accommodation 1976/7</u>	
Children and adults	42
<u>Crisis Assistance</u>	
Children and adults given this help for a total of 1,179 days (duplicated figure)	125

CMH would like to express its gratitude to the staff of ENCOR for patient and willing help in compiling figures used here and elsewhere in this report.

ENCOR - A Way AheadINTRODUCTION

In Eastern Nebraska, USA, those concerned with the dignity, welfare and development of mentally handicapped citizens and their families are well on the way to achieving a goal which we in the United Kingdom have not yet been prepared to set ourselves. The goal is to serve mentally handicapped people of all ages and degrees of disability in their own home community.

The agency charged with providing this service is the Eastern Nebraska Community Office of Retardation (ENCOR), which started in 1970 and is based in Omaha, the largest city in the State. Already, ENCOR is well on its way to achieving its objective. Within seven years of its inception, 259 of the children and adults from Eastern Nebraska living in the State institution had been able to return to their home communities. By 1974, community services were sufficiently developed virtually to avoid admissions or re-admissions to the institution; only about 15 people have been admitted from the ENCOR area since 1973. To make this possible, ENCOR has developed a range of family support, accommodation, developmental, work and training programmes which, together with generic services, is able to meet the needs of its mentally handicapped citizens, however disabled they are. While it has not been possible, because of financial constraints, to maintain the spectacular rate of discharge from the institution - there are still nearly 300 people from the ENCOR area living in the Beatrice State Developmental Centre - ENCOR is still serving some 900 clients.

Between 1974 and 1977, all three of us had the opportunity to visit Eastern Nebraska to gain first-hand knowledge of ENCOR's exciting and innovative programmes. The purpose of this report is to share some of our experiences. ENCOR has now been operating for over seven years; it is no longer an "idea", untested by experience. It has been providing far more flexible, client-centred and comprehensive services than any in this country for longer than the White Paper "Better Services for the Mentally Handicapped" has been published. It continues to provide them in spite of a severe financial crisis in 1975/6.

Those of us who are concerned with services for mentally handicapped people in Britain should now be examining closely the principles, objectives and organisational strategy outlined in "Better Services for the Mentally Handicapped".<sup>1</sup> Our present economic difficulties, instead of being a source of frustration and despair to those of us who are committed to developing alternative systems of care, may provide us with a breathing space and a vital opportunity to rethink. In the 1960s, we looked to the Scandinavian countries for new ideas. In the 1970s, much could be gained by careful examination of developments in certain parts of the United States and Canada. We have much to learn, not only about the principle of normalisation in the design of services for handicapped people, but also about the dynamics of change in human services.

The Beginnings

Nebraska is a mid-Western state, with a reputation for conservatism: it has been called "a hotbed of republican reactionaries". Its total population of 1.5 million is largely rural; some 400,000 people live in and around Omaha. Why should Nebraska have become the home of such a comprehensive and creative service for mentally handicapped people? More important, how was such a system started and brought to its present state of development within such a short time?

Beatrice State Home, the State's one major institution for mentally handicapped people, was itself a necessary but not sufficient condition. Situated **over** 100 miles from Omaha, in 1968 Beatrice accommodated over 2,300 residents in deplorable, overcrowded physical conditions. Official reports<sup>1</sup> and subsequent press coverage were to emphasise that this form of restrictive and savage institutional care was archaic, immoral and wasteful. All three of these evaluations were to have an impact. The average costs per resident were, in 1968, just over half the national average and less than one-third of the costs in some of the "better institutions" in the USA. Despite the conditions at Beatrice, however, it seems unlikely that significant changes would have occurred in Nebraska's system of care for mentally handicapped people, but for three other factors.

The first was the existence of an angry pressure group - the parents. They were joined together in a state-wide association (the Nebraska State Association for Retarded Children)\* as well as local groups. The Greater Omaha Association for Retarded Children\* (GOARC) became particularly important: its members are drawn from Douglas County, where Omaha is situated.

The second factor was the local presence of a number of intelligent, articulate and concerned professionals with an international perspective and involvement in planning at a national level. This group included Frank Menolascino, Associate Professor at Nebraska's Psychiatric Institute, Wolf Wolfensberger, Research Psychologist in the same Department, Robert Kugel, Director of the Growth and Development Institute at the University of Nebraska, and also a member of the President's Committee on Mental Retardation, Richard Meile, Associate Professor of Sociology (and also the parent of a retarded child), and George Thomas, Director of the State Division on Mental Retardation. Unlike many of the interested professional workers in Britain, none of these had any vested professional interest in defending and maintaining large institutions.

The third factor was a mutual concern for mentally retarded people and a recognition that the only way significant change could come was through joint action of parents and professionals. Without each other, neither group could have achieved its purpose.

This joint action had a number of closely related outcomes. The first was two comprehensive planning reports. One of these was the work of the Citizens' Study Committee on Mental Retardation, which had been established by the State Government in 1967 at the request of the Nebraska Association for Retarded Children. Originally, its brief had been to evaluate and report on conditions in Nebraska's State Institutions, but this brief was extended when it became evident that the problem of the large institution could only be solved in the context of a complete reappraisal of all services throughout the State. The Committee worked through an extensive survey, written submissions, which it invited, and public hearings. The result was a three-volume report, published in July 1968. This provided a detailed and radical plan for new services for mentally handicapped people.

The Committee based its work on five principles, which in the context of the time at which they were drawn up give an indication of the far-sightedness of its approach.<sup>1</sup>

- "1. No matter how handicapped, a retarded person or institution resident is not an animal, vegetable or object, but a human being and a citizen, deserving of respect and in possession of certain human, legal and social rights. As much as possible, retarded persons, whether

institutionalised or not, should be treated as ordinary persons of their age are treated in the community. Every effort should be made to "normalise" retardates, that is, to diminish those aspects that differentiate a retardate from a typical citizen of comparable age.

2. There should be maximal continuity of contact and atmosphere between all phases of service agency (including institution) functioning and the community.
3. Continuity of contact between a retardate and his family should be maximal, limited only by liberally interpreted considerations for the welfare of the retardate, his family and the agency (for example, institution) serving them.
4. Service agencies (including institutions) should provide an environment conducive to their clients' physical, intellectual, social and emotional well-being and growth, with special emphasis on the development, welfare and happiness of children.
5. Each retarded person, particularly if he resides in an institution, should have a special relationship to a competent individual citizen who will act as his personal advocate, vigorously representing his interests and safeguarding his welfare."

(The term 'retardate' has since, of course, passed out of usage altogether).

The second planning report was produced by GOARC, for Douglas County. This plan, "structured so as to be consistent" with the state-wide report, was informed by a common philosophy, based on normalisation. The consistency of these two reports was to have a decisive compounding influence, and was assured by the fact that four people were on both committees.

What was special about these reports other than their consistency? There had been others in Nebraska which, like many in Britain, had evoked only mild interest or indifference and had failed to be implemented. The following factors seem to have made the 1968 reports special:

The reports had a well-thought out philosophy, informed by Scandinavian thinking, adapted and further developed to apply to the local situation. They demanded normal citizens' rights for mentally handicapped people. They had extensive data on clients, services and costs. They focused on the vast financial cost of providing inappropriate services to mentally handicapped people and their families and emphasised that, given the opportunity, mentally retarded children could grow into adults who could contribute to society. They specified legal and organisational changes, and the major elements of a comprehensive programme of services. In particular, the establishment of a single agency to serve all mentally handicapped clients was to prove decisive, as was the setting of specific targets for the short, medium and long term. Finally, the way the reports were produced and publicised, coupled with their creative content, made for their success.

(5, 6)

Wolfensberger has examined the determinants of success in some detail. Those appointed to the Committees were selected for their planning ability rather than because they represented a particular agency, or because they held powerful positions within existing service systems. The strong involvement of academics who had nothing to lose by a change in these systems is an important illustration of the principle. Consumers were represented on the Committees and were charged with much of the data collection and report writing, as well as with publicising the reports and

gaining widespread acceptance; for them. The planning was conducted simultaneously on several levels. And finally, the Committees, slightly enlarged, **were** charged with implementation after the publication of the reports; this ensured continuity and drive.

When the report of the Citizens' Study Committee was accepted in 1968, the planning group started to work on implementation. The help of a sympathetic professor of law was enlisted and 14 bills were placed before the State Government. Some of these aimed at immediate improvement in care within the State institution: these included measures to introduce mandatory periodic inspection by the State Department of Health, higher and uniform pay scales, job evaluation and staff training programmes. Others were designed to abolish mandatory sterilisation review and the possibility of compulsory sterilisation as a pre-condition for discharge from the institution. Other bills were designed to help the development of alternative community-based programmes. Nearly all these bills evoked considerable controversy. However, intensive lobbying of Senators, together with a great deal of publicity through television, radio and newspapers ensured that all 14 were successfully carried. It was these bills which provided the framework for the development of a wide variety of community-based programmes throughout Nebraska.

In particular, the State plan and the new Acts encouraged the Douglas County Authority to accept GOARC's plan and to make a commitment to serving all its mentally handicapped citizens within the community. In 1968 and 1969 the authority provided funds to enable GOARC to establish certain pilot demonstration projects. In 1970, it persuaded four adjoining counties to join with it to establish the Eastern Nebraska Community Office of Retardation.

#### THE GROWTH AND DEVELOPMENT OF ENCOR

Charting ENCOR's success is not an easy task. It is the story of continuous progress and change. It is also the story of how an organisation with a basically sound foundation can adapt rapidly to new challenges.

ENCOR provides services to five counties of Nebraska, with a total population of 569,600. It includes both urban and extensive rural areas, with the city of Omaha which is in Douglas County and 4 rural counties. The boundaries of ENCOR's area lie about 50 miles from Omaha.

Since the service was set up in 1970, there have been some reorganisations within it. There are now four main divisions: Educational Services, Vocational Services, Residential Services, and Family Guidance. There are in addition a Planning Department, a Public Education Department, a staff development team responsible for staff training, and a "transdisciplinary" professional team, which serves the four main divisions.

#### Educational and Vocational Services

GOARC, in its initial pilot project in 1968/9, and indeed before this, had followed the common pattern of many parents' groups, in both the USA and Britain, by concentrating on educational and vocational services. This is understandable, as many parents wish their children to live at home and have found them denied opportunities for education or work. In Nebraska, children with a severe degree of mental handicap were denied education until 1973, when a State "Right to Education" Bill was passed. Now, all children, including the most severely handicapped, have access to education within the normal State system.



When GOARC handed over its pilot projects to ENCOR, it had established one "developmental centre" (special school) in a rented church basement. By 1973, ENCOR was serving 225 children, aged between 2 and 12, in six special schools. Since then it has concentrated on moving children into the normal State school system, in special classes in ordinary schools.

#### pre-school education

By 1974, within two years of the start of the integrated pre-school programme, 56 children for whom ENCOR was responsible were in integrated pre-schools. By 1976, this number had risen to over 100, distributed among nearly 20 creches and nurseries, and almost all living at home with their parents. In addition, ENCOR runs its own pre-school day care programmes: in 1977, there were 9 of these, catering for 60 children between two and five, as well as 11 children receiving "home training".

*In one school visited, there were 45 children, nine of whom were handicapped. The staff consisted of the Director, 5 pre-school teachers and two permanently attached ENCOR teachers: each of these had special responsibility for four or five handicapped children, with whom they ran individualised language, self-care and other developmental programmes. Most of the children's time, however, was spent in activities with the non-handicapped children. The physical environment was excellent, the school was amply provided with toys and equipment and the programmes were similar to those one would see in a pre-school in this country. ENCOR children seemed well integrated, as did staff, although there did seem to be a degree of understaffing. In all, the programme was Very impressive.*

ENCOR is encouraging two types of integration at the pre-school level. The programme described above is a "cooperative" playgroup or nursery, where the handicapped children are in a group supervised by ENCOR-paid staff and spend only part of their day with other children. There are also completely integrated playgroups and nurseries, where the handicapped children do not form a special group, and spend their whole day with the other children. In these programmes, there is normally one ENCOR-paid and specially trained member of staff; he or she, however, works with all the children and not just the handicapped ones.

#### Primary and Secondary Education

Each year since 1973, up to 60 mentally handicapped pupils have moved out of ENCOR's special schools into the regular State school system. By the end of 1976, when 57 children moved out, all six of ENCOR's own schools had closed; all the pupils had moved into the regular system, except for five still in an ENCOR unit.

This includes the children said to be most "difficult". One of us (AK) visited a "transitional" unit for such children in 1975; all are now in special classes in ordinary schools:

*A group of about 12 children, aged between 7 and 16, who had lived either at home or in the State institution, were said to show such emotional or medical difficulties that they could not be accommodated within an ordinary school. These children were reckoned by ENCOR to be the most difficult on their books, and the agency had at first provided a special, separate unit for them. It then, however, decided that these children too had the right to receive education in a normal school setting, and so it found a high school which agreed to rent it a classroom, and ENCOR provided all the staff.*

*By the time of my visit, this special class had been going for just three months. Its integration into the "host" school had been a major*

achievement. The other children in the school had proved extremely supportive to the ENCOR children; these children had already made considerable progress. The success of the venture can be measured by the fact that they are now all dispersed into special classes within ordinary schools.

This push towards integration has not been achieved without difficulty. To increase acceptance and to maintain the quality of educational programmes, ENCOR teachers have provided advice and support to the ordinary schools; they have also sometimes moved into the schools themselves to provide extra resources. Some "special" teachers admitted that the teachers of the "normal" children had objected both to them and to the presence of the handicapped children. The "special" teachers had sometimes found it hard to maintain the quality of teaching programmes, because they felt they lacked opportunities to exchange ideas with the "normal" teachers. They admitted, however, that these were still early days.

#### Special Educational Units for Adolescents

The history of these illustrates the success of ENCOR's approach. They were set up at a time when there were no integrated facilities for these young people, but, thanks to ENCOR's own activities in changing educational policy at State level, they were soon largely superseded by more integrated arrangements.

The two special units started in 1973, for adolescents aged between 12 and 18 who were excluded from the State schools because of the extent of their handicap. A year later, there were 50 young people in this programme and a number had managed to move successfully into the State schools. While some of those at the centres would have been described as ESN in Britain, others would clearly have been categorised as ESN(S).

One of us (DT) visited one centre in 1974:

The staff consisted of a Director, a trained teacher with psychology degree, four teachers and four assistants. This provided effective staffing ratios of 1:3. A speech therapist and physiotherapist provided extra help. The programme operated for five days a week, between 8.30 am and 3 pm. Most of the students were living at home, but a few were in ENCOR residences. The main problem, apart from rather limited classroom space, was a lack of age-appropriate educational materials - a problem we share in this country. The main focus of the curriculum was on language, motor development and group interaction, as well as on self-care for those who needed to learn these skills. At the age of 17 or 18, these young adults were gradually introduced into the vocational centres.

Two years later, ENCOR was responsible for only 5 of these 50 students. These five too, should soon be served within the normal school system; ENCOR planned to close the unit they now attend at the end of 1977. Even though conditions within the ordinary schools may not be ideal, these young people will have the advantages of being in a special class, with special teachers, as well as those of being in a regular school building. Their "normal" peers will clearly benefit from their presence as well.

The low cost-effectiveness of Nebraska's institution-based programmes for mentally handicapped people had been emphasised in the 1968 analysis. In particular, it was argued that custodial approaches not only denied handicapped adults the opportunity to enjoy work as a normative experience, but also deprived the State of economically productive manpower. Many handicapped people, it was argued, were potential taxpayers rather than tax-takers, and handicapped adults could at least offset some of the costs of services. So the development of Industrial Training Centres was seen as

a high priority by ENCOR. By 1974, there were five such centres, very similar to Adult Training Centres in Britain. By 1977, there were four Centres, serving a total of 217 workers, and one advanced training centre, North East Industries, serving 42.

Initially, the emphasis in these centres had been on further "social education", involving classwork and visits to the community; work occupied only a part of the daily programme. This had proved very staff-intensive and exhausting for the teachers, so it was decided to switch the primary focus of the programme to work-training, using work subcontracted by local industry. These work programmes, like the majority in Britain, occupied the mentally handicapped person's day rather than preparing him or her for open employment. Now, however, there are some important differences from our own ATCS. The aim is to provide an initial period of work training and evaluation which can last up to 18 months, and which concentrates on developing work habits and motivation together with job-related behaviours - how to apply for a job, succeed in an interview, and so on. After this period, the handicapped people either join a work programme within the Centre, or move on to more independent programmes. These include an advanced training centre, North East Industries, half a dozen work stations (see below) and, for the most able, a short job placement course.

There is a great deal of flexibility for the individual client within this system. Over a quarter of those at one training centre moved on to North East Industries in 1976/7. Since this programme started, in 1975/6, more than half its clients have moved on to work stations - about one in 10 of them returning because the placement was unsuitable and others while temporary problems were sorted out.

These are the impressions of one of us (AK) of a visit to an Industrial Training Centre: *As with other aspects of the ENCOR programme, I was impressed with the individualised approach to people attending the centre. For example, I saw one young man who had a member of staff sitting with him throughout the time I was there. This young man had been attending the centre for 12 months and because of his aggressive behaviour, had to have a member of staff with him the entire time. During this period, his behaviour has become more controlled and he is able to carry out part of one of the work processes. When I expressed some surprise at the amount of individual attention this young man received, I was told that in the past two years the centre had had three others who had needed - and received - as much. In time, this had paid off: they are now able to cope with a full day in the centre without constant attention. This was particularly impressive, for I saw people at this centre who would be unlikely to be accepted in an ATC in Britain, because of the degree of their handicap. I got the very firm impression from staff that they regarded the unit very much as a training establishment, where they trained their work people to be able to cope in a more normal work environment.*

By 1971/2, ENCOR had realised that progress into open employment was slow and that the demand for Centre places was soon likely to outstrip their capacity to provide. In an effort to anticipate this problem, and to provide more normal work experience, ENCOR began to develop "work stations" within industry.

This involves placing a group of handicapped workers with their own instructor in manufacturing or service industries. Payment for the group as a whole is negotiated with the firm and ENCOR in turn pay their clients according to their productive ability. The first work station involved ten handicapped workers in a shop-fixture manufacturing **company**, the next

involved placing a team of eight women as cleaners in a Holiday Inn.

*At one work station visited, at a large general hospital, a group of men and women were operating, in several shifts, a dishwashing machine. The work was arduous and, because of its seven day a week nature, very demanding for the supervisor of the group. But the group seemed well integrated as part of the kitchen staff. In a metal plate factory, a team of men were engaged in cleaning and stripping work. One of this group had moved on to join the main work force; he was paid the full rate for the job and had become an active member of the trade union.*

By 1975, some 75 people were employed in work stations and between 1970 and 1975, nearly 100 people had moved through to competitive employment and generic job-training schemes. In 1977, there were five work stations, employing 73 people. Of these, a total of 33 were in two work stations at the shop-fixture manufacturing company.

#### Trends in vocational services

The number of ENCOR clients who have been able to find open employment has recently been dropping. In the present economic climate, it is proving harder for anyone to find jobs. ENCOR's work placement service (which includes job readiness training, job counselling, placement and follow-up) was only able to find jobs for 40% of clients served in 1975/6, compared to 100% in previous years - nearly two-thirds of them in the restaurant and hotel trade or laundries. Nevertheless, 31 people moved from ENCOR's own services to open employment during 1976, and it was able to find jobs for another 45 people who came to it from other sources.

The second reason why fewer clients are being found jobs on the open market is familiar to most of us in this country who have started to help people move from restrictive institutional settings to more normal ones. Initially, many able people move quickly into ordinary accommodation and/or jobs. But gradually, the clients served are more handicapped and it becomes progressively more difficult to enable them to move on. The situation can only become harder for ENCOR as time goes on, if it continues to depend on a step by step progress from training centre to North East Industries to work station. This problem arose for ENCOR's residential services some years ago and there - as we shall see - it replaced the step by step system by one which moved people straight to the "least restrictive environment", with a great deal of staff support if they needed this. In ENCOR's vocational services, staff are just beginning to tackle the parallel problems and may adopt a parallel solution: to move even extremely handicapped people straight to work stations or open employment, providing the staff to support them in this environment. Whatever solution is adopted, it is as likely to be as creative as that to other problems ENCOR has encountered in the past.

#### Other vocational programmes

The vocational placement service, besides including placement services and job counselling follows up each "ex-client" routinely for three months. Evening meetings are also held for working people to discuss their experiences. Job readiness training covers the types of jobs available, why people work and the skills needed for job-hunting, making applications and coping with interviews.

These programmes were augmented in 1974 by a social training scheme and evening education. The first involved resource instructors who were responsible for intensive short-term programmes to improve social and personal skills. The evening education programmes were also run by ENCOR staff, using community facilities whenever possible; here the emphasis was

on academic skills. Both these services fell victim to the financial cuts and have been stopped altogether.

Residential Services: accommodation for mentally handicapped people

It is perhaps in its attempts to conceptualise, develop and organise accommodation that ENCOR has shown most creativity. Frustration at what the agency saw as slow progress towards their personal and public goal of enabling all Eastern Nebraska's mentally handicapped citizens to continue to live within their home communities has led to inventiveness and a return to basic principles.

Hostels

The planning reports had outlined a system of small residential units designed to meet the needs of particular groups. It had been recognised from the outset that small was beautiful if integration into the community was to be achieved. Most of these units could be described as small "homes" or "hostels", and the intention was to use existing housing wherever possible. The units included group homes for up to six pre-school children; similar homes were proposed for children between the age of 5 and 10 and for adolescents. Accommodation for adults was to include short-term training hostels for up to nine young people, longer-term hostels for the moderately handicapped and minimally supervised hostels which would offer land-lady type support. In addition, a number of more specialised units were proposed. They included maintenance of life' units - subsequently called 'developmental maximisation units' - for multiply-handicapped children and adults with major medical needs, short-term 'crisis assistance units', designed to provide families with temporary relief from demanding home care, and 'habit shaping units' for the more severely and profoundly handicapped adults without a need for intensive medical intervention. A 'structured correctional unit' was also proposed for mentally handicapped offenders, as an alternative to prison. Finally, it was considered that aged mentally handicapped people should be cared for in the geriatric nursing homes which already existed within the community.

The central concept was therefore of a range of relatively small, staffed hostels dispersed throughout Eastern Nebraska. The concept of a regional centre, which attempted to provide services for mentally handicapped people with widely differing needs in a complex remote from their home communities, was rejected.

In 1970, ENCOR had inherited two hostels from GOARC. By late 1973, there were 12. Three of them were for boys and girls, one was for adolescent boys and eight were for adults, only one for both men and women. Together, these hostels provided about 70 places. All involved the purchase, or more often the renting, of existing property - usually the older and larger "town houses". (It is typical of ENCOR's flexibility that it used to buy houses, until it found that this did not enable it to respond to clients' changing needs. Now it never buys houses, but always rents them. Our own health authorities and social service departments might learn from this experience, especially in these times of financial stringency).

One of us (DT) visited hostels in 1974:

*The first was for six children - two girls and four boys. The house was a large, single-storey one in a residential district of Omaha, It staffed by a married couple, one relief houseparent and two fulltime and one part-time residential assistants. The children had been living there since 1970 and clearly saw it as "home"; there were close relationships between them and their houseparents. There was ample evidence not only*

of a high standard of child care but also of sophisticated individual teaching programmes. The children were said to be well accepted by others in the area, but the houseparents seemed to feel that even greater progress could have been made if the group had been smaller.

The adult hostels consisted of large town houses. Most of the residents had single rooms; there was a wide range of choice. All the residents worked during the day, mainly in the training centres, a few in work stations; most attended ENCOR's Varied recreational programme during the evening. Again, there was evidence that the residential staff took seriously the maxim that bricks and mortar do not make a programme. Most of the staff were actively critical of the degree of progress being made and most wanted to see the development of smaller, less restrictive accommodation - this, despite the fact that the programme compared very favourably with the best available in Britain.

The most highly staffed hostel visited had two "live-in" houseparents - a married couple - one relief houseparent, one full-time and two part-time assistants, for eight adults. Main meals were cooked by staff, helped by residents. The least staffed hostel, where some of the most able ENCOR clients lived, had one "live-in" housemother and one relief houseparent, again for eight residents.

By 1977, there were seven hostels, or "training residences" as they had now become, for a total of 31 children and another seven for a total of 31 adults. The fact that the number of residences had hardly grown in three years and that the number of people in them had actually fallen, does not, however, mean that ENCOR's provision of accommodation had remained stagnant. Far from it, as we shall see below.

#### The crisis assistance unit and short-term fostering

Crisis assistance to families with a mentally handicapped member was seen as a high priority and in October, 1971, a house was rented in the centre of Omaha to provide short-term residential care for up to six children or adults. This was run by a married couple, the wife trained and employed by ENCOR, with support from other ENCOR staff, including one person responsible for leisure programmes; whenever possible, residents continued to participate in their regular daily programmes while in the home. Parents and ENCOR staff worked out criteria for use of the unit: first priority went to families with an immediate crisis, like death in the family, the need for the person most responsible for the care of the handicapped person to go into hospital, or the loss of a previous residential placement for the handicapped member. After this, priority went to families where relief of immediate stress - like that of moving house - might prevent more serious crises in future. And finally, the unit was designed to help families whose handicapped member demanded almost constant attention, so that other members could get a holiday, for instance. In the first group, clients could stay for up to six weeks in the unit, in the second, for up to a month and in the third for two weeks in a year.

It soon became evident that there were limitations to such a unit. It was remote from the rural parts of the ENCOR area and so, like short-term care in institutions, took the client away from his or her own neighbourhood, bringing disruption to educational and vocational programmes. The cost of creating similar units in rural areas would have been prohibitive, as they would have been under-used a great deal of the time. In addition, fire regulations restricted the use of the unit to people who could walk.

So, in 1972, ENCOR began contracting with families who were prepared to take a mentally handicapped child or adult into their own home on a short-term basis. This model became known as "crisis homes"; in Britain, they would be termed short-term foster homes. Priority was given to the same groups who used the crisis assistance unit, with a possible stay of one month. One person only was placed in a family at any one time and one member of the family - usually the mother, who remained at home during the day - was employed by ENCOR and given the same training as the staff of the crisis assistance unit.

The original crisis assistance unit and the crisis homes fell victim to the 1975/6 financial cuts. The unit was closed in March, 1976 and the homes themselves were unable to take any more children - for whom the service had mainly developed - for four months. The re-opening of the unit remains a priority, because clients do not like others coming into their own hostels for short-term care, and because there are still not enough families to meet the need of all ENCOR clients for crisis assistance. Nevertheless, there were 125 "stays" by children and adults in crisis assistance homes during 1976/7.

#### The behaviour shaping unit

This teaching-living unit developed originally as part of the educational and vocational division, but was transferred in 1974 to residential services. It was a programme for eight children and young people, aged between 10 and 19, most of whom had come from Beatrice institution. Overall staffing ratios in the large house were just over one to one. The aims of the programme were to develop self-help and social skills in severely handicapped and disturbed children and to reduce maladaptive behaviour. The staff had been very well prepared for the task, but by 1974 they were admitting that the programme had not been very successful. By the end of that year, ENCOR had decided to integrate the children into smaller residences. It was felt that this would have a number of distinct advantages. The children would be living with others who were less handicapped and so would have more normal peer models. They would be encouraged to attend school, which would achieve a more normal separation of home and school environments. Finally, it was felt that this arrangement would be less stressful for both houseparents and teachers; those who had tried to combine these roles within the behaviour shaping unit and to maintain intensive programmes, had found the task a formidable one.

In 1977, staff were saying quite simply that the behaviour shaping unit had been a mistake: the children had learned undesirable behaviour from each other, while living with more normal peers had led to more normal behaviour. The early and frank recognition of its mistakes and rapid correction of them is typical of ENCOR. How common is it in British services?

#### Structured Correctional Units

A special grant from a programme for mentally handicapped offenders had allowed ENCOR to add a programme for them to its already impressive list of residential options. This involved one well-staffed group home and two staffed apartments, serving 11 clients in all. This was, however, one of the programmes cut in the 1975/6 crisis. At present, it looks unlikely that it will start again within the next year or so.

#### Developmental Maximisation Unit

This unit was established in 1972 in an unused wing of Douglas County Hospital, to provide residential care with a strong emphasis on develop-

mental programmes for up to 16 multiply-handicapped and medically involved children. Residential services division took responsibility for it in 1974; originally, it had been part of educational and vocational services.

This is how the unit struck one of us (DT) in 1974:

*Every effort had been made to make the unit as home-like as possible. There were carpets on all the floors, the furniture was domestic in nature and the decor bright and airy. There were curtains at the windows and pictures on the walls. The children slept in small rooms. The unit's director was a woman with both nursing and social work qualifications; five qualified nurses provided 24-hour cover and the teaching and developmental programmes were provided by 15 'teachers', supported by a physiotherapist. The unit was administratively completely separate from the main hospital, but there was immediate access to emergency medical services and paediatricians were on call' 24 hours a day. This well-developed programme was undoubtedly providing both high quality nursing care and developmental teaching programmes as good as, or better than, others in high-cost institutions in the USA. Most of the children had originally come from Beatrice Institution, often in poor physical and medical shape. Several had been helped by long overdue surgery. Between 1972 and mid-1974 23 children had passed through the unit to other forms of residential care.*

*Jennifer had been living in the unit since 1972, and was now three years old. She had been admitted to the Beatrice Institution when she was three months old, after operations for spina bifida and hydrocephaly. Her parents had been told she would never be able to do anything for herself or respond to the world about her. When she moved to the Developmental Maximation Unit she had a chronic urinary infection which was threatening her life. Eventually, the condition was corrected by another operation and her physical improvement after that was dramatic. By September 1973, she had improved enough to go to an ENCOR pre-school programme; the following year, she moved to a pre-school for normal children. ENCOR staff said she had had a "language explosion" and would imitate almost anything said to her. She had also learned to manoeuvre herself independently on parallel bars, take her own wheelchair all over the unit and learned all her own body parts, including her legs and feet, in which she had no sensation. She now went home to visit her family frequently at weekends.*

In 1975, the DMU suffered severe staff cutbacks, and as a result the number of children in it fell to six by May 1976. This has not, however, proved the disaster it would have been. None of the children who had to be found other accommodation returned to Beatrice Institution. All were found either foster homes or a place in a staffed hostel - and these 10 children were said to need "24-hour medical and nursing care!"

In 1977, the DMU had a total of 17 staff, including five registered nurses; on any shift, three staff (one qualified) were on duty. In April 1977, there were five children in the unit, most of whom had cerebral palsy, epilepsy and medical problems such as pneumonia. The staff felt that it was crucial to be able to get to know the children well and spend time with them, and that in any other ward their care would have been custodial and medical. The overall ratio of staff to children of three to one is very high by any standards; the unit is known as a "cadillac ward" in the rest of the hospital.

The policy now is that the unit should provide evaluation of children with multiple handicaps who have come from the State Institution, or of others



with multiple handicaps or medical problems, and that no child should spend more than one year there. It is also a setting which can cope with children who need life-maintenance skills, so it offers both assessment and intensive care.

From the time the unit started in 1972 to mid-1977, sixty one children had moved through it, five of these during 1976/7. In all, 34 children had gone to their own homes, 11 had died, eight had gone to 'alternative living units' (see below) seven to other ENCOR residential homes and one into foster care.

It is worth emphasising that the DMU is the only institutional accommodation offered by ENCOR. Nowhere else in all its residential services are more than 6 children or 8 adults gathered in any one house. Even the DMU, in mid-1977, had only 6 children.

**Alternative Living Units** group homes, shared flats and foster homes

By the end of 1973, ENCOR was beginning to have problems, especially in providing accommodation for its clients. These problems included escalating staff costs, high staff turnover and an inability to recruit enough high quality staff. Capital costs were also increasing and the time lag between planning and opening a unit was lengthy; fire and zoning regulations were posing extra difficulties. (Ed Skarnulis, then head of the residential services division, has analysed these problems in some detail and an extract from his paper is at Appendix 4).

Faced with these problems, the residential services division began to consider seriously whether 'group homes' really represented the least restrictive alternative for the children and adults who were coming into them. They concluded that they did not. They also concluded that if more intensive practical support was offered to families, this would reduce the demand for long-term residential care; short-term relief care, or fixed term care, should be offered whenever possible.

The establishment of 15 developmental homes - long-term, single-child foster homes - which had begun in 1972, had been an important step towards more normalised and cost-effective approaches. So had the development of apartments, rented by ENCOR, who contracted with a non-handicapped person, often a student, to act as flat-mate to between one and three mentally handicapped adults, providing support, guidance and friendship. Now it was decided that far more emphasis should be put into smaller, more normal living - foster homes for children and a whole range of independent and semi-independent living for adults. Requirements that clients should reach certain levels of skill before moving from a staffed group home to an apartment or from the latter to independent living, were questioned. It was concluded that many of ENCOR's clients were capable of much more independent living, provided that they were offered additional skilled domiciliary support. Finally, it was agreed that the community had untapped resources in people who would provide a home or support on a contractual basis.

The term 'alternative living unit' was coined to help the agency's staff think flexibly about the development of new alternatives in accommodation and a more creative use of existing facilities. Administratively, the residential service division was decentralised and staff were encouraged to use their initiative to develop a satellite system of ALUs, using an existing group residence as the core and back-up facility. For example, one training residence has six children; three more have moved through into foster homes and four, in pairs, to new ALUs. The foster parents are called 'home teachers' to help reduce the resistance of natural parents to a move from a staffed residence.

One of us (AK) visited several ALUs:

J was impressed by the tremendous flexibility that this system offered. In one alternative residence, an apartment in a block, a young lad in his early teens lived with two full-time members of ENCOR's staff. This young man had no speech and very severe behaviour problems; he had attacked and battered several women in the past. After five months in the apartment, he had settled down considerably, and a week or so before I visited, a second boy had successfully joined the apartment. When I was there, the staff were trying, with some success, to bring women to the apartment to visit, in the hope that the first boy would gradually learn to accept the presence of women.

Another ALU I visited was a private house, owned by a policeman and his wife, who had taken in two retarded boys, now 17 and 18. This was close to a foster-home, in British terms, but with the difference that the couple could turn to the core residence to which they are attached for relief and support; the wife was actually on the ENCOR staff.

This change in direction allowed ENCOR to expand its accommodation for children and adults from some 90 places in 1973/4 to 220 by 1974/5; during that period, the number in Alternative Living Units rose from 51 to 157. The financial crisis meant that ENCOR could take no new referrals for nine months and the following year some 20 fewer people were in the agency's accommodation. In mid-1977, however, ENCOR was providing accommodation for some 230 people, of whom 90 were children. There were 32 Alternative Living Units for children, offering homes for 53 in all and 64 for 110 adults. During 1976-7, 42 new clients were accommodated by ENCOR, 31 from the community and 11 from institutions. Over the same period, seven children moved out of ENCOR accommodation (two died, three went home and two moved out of the region) and so did seven adults (four either set up house on their own or moved home, and three moved to different institutions).

In spite of its recent financial troubles, ENCOR has a truly impressive record in providing accommodation in small houses for both adults and children. No child in an ENCOR house lives with more than five others; in only three houses in the whole area are there as many as six adults. Staff establishment averages out at about one for every client.

ENCOR has tried to show that all mentally handicapped people, with the exception of a very few who have multiple handicaps and pressing medical needs, can live in ordinary houses with the support that is necessary. They have demonstrated this very clearly for children, although not yet, in large numbers, for adults. In April 1977, however, some profoundly handicapped adults, without basic self-help skills and in addition wheelchair-bound, were moving into ordinary houses, with staff support for 24 hours. Interestingly, it was again the financial crisis which helped ENCOR to look for less restrictive accommodation for such very handicapped adults. Having started an Adult Multi-Handicapped Programme in a "core medical unit" in a local nursing home, it was then obliged to close this, but was able to find its first two clients homes within the ENCOR network of accommodation.

One of ENCOR's priorities remains, as it always has been, to find alternative accommodation for all the mentally handicapped people from its area who are still in Beatrice State Institution. It has, naturally enough, started with the more able residents of the institution, which is why it is only now tackling the question of finding the best accommodation for adults with profound and multiple handicaps. When ENCOR started work,

there were some 550 people from its region in Beatrice State Institution; there were 290 in mid-1977. Between times, the waiting list for the institution in the ENCOR area fell from some 40 to no one at all. And between mid-1973 and mid-1977, the number of admissions or re-admissions from the ENCOR area to the institution was about 15; in six of these cases, ENCOR had either offered a place or had not been informed of the admission. In spite of its financial problems, ENCOR has amply made what is perhaps the most important point of all for the future: there is no need for any admissions to large hospitals, once adequate community-based facilities have been developed. As long ago as 1974, ENCOR showed this when admissions to Beatrice State Institution, which had been running at an average of 10 adults and two children a year three years earlier, stopped altogether.

One final and critical reason for ENCOR's success in finding accommodation in the community for so many mentally handicapped people is worth noting and learning from. While both children and adults need learning experiences and occupation during the day, this is by no means guaranteed for adults in Britain. In the ENCOR service, the Vocational Division guarantees a place in a training centre for every adult. The advantages of a common policy, set by all those involved in the life of the mentally handicapped individual, are clear.

#### Family Guidance Services

This vital division of ENCOR provides the main support for and co-ordination of services to clients and their families, as well as support to staff in other divisions already described. Family Guidance Services at one time included initial handling of all referrals, client counselling, psychological and medical services, speech therapy and physiotherapy, transport, recreation and clients records. It was this division which originally developed the Crisis Assistance Unit, crisis homes and foster home programme.

In 1977, the division had the following roles:

1. Central Enquiry: The division acts as the initial referral point for all requests for ENCOR services. There is a small centralised team of three people in Omaha, who know the full range of ENCOR's services and those of other agencies. This team provides initial information to clients, their families and other agencies, and/or refers them to the appropriate field advisors. There are about 30 enquiries a month. This team is also responsible for maintaining full information on clients, ensuring that records are updated, and on services - including vacancies, number of social worker - client contacts made and decisions made about clients.
2. Child and Adult Counselling (Casework): After a request for service has been made through the central inquiry office, a neighbourhood advisor visits the client. He or she is responsible for decisions to use ENCOR's direct or indirect services, for providing information to the client or for referring to another more appropriate agency.

For clients in the ENCOR system, the advisor is responsible for providing support to families or adults living in their own homes, for helping to organise specialised services and for coordination of the individual programme plan. The last has become an increasingly important part of the advisor's job. It is now ENCOR's policy to review each client's individual programme plan every three months.

At the moment, the review is six-monthly, for every client who receives any services of any kind.

3. Support Services: These include transport - usually through contracts with local taxi firms - a toy lending library, a central record system and coordination of voluntary services. Wherever possible, needs are met through existing facilities, available to non-handicapped members of the community. So, for instance, psychiatric services are provided by the Nebraska Psychiatric Institute; ENCOR pays a fulltime worker at the Institute to act as liaison for mentally handicapped clients.

By 1973/4, five decentralised area offices of this division had been established. By 1974, the division was serving a total of 1242 clients and anticipating that this number would increase to 1600 over the next year. But the Family Guidance Division was the hardest hit of all by the 1975/6 financial cuts. By early in 1976, the 34 advisors had been reduced to 19, plus four senior staff, and new referrals were refused for 10 months. Staff numbers are now up again and advisors have an average of 40 clients, of whom three quarters need active support. Each client is visited at least once every three months, or every six months if they need only "follow along" supervision. (Clients living in unstaffed ENCOR accommodation are visited at least once a week by residential staff).

#### Staff Training and public education

ENCOR has always emphasised the importance of training and continuing education for its staff and education for the public. At one time, both functions came under one division - now there is a Public Education Department and a separate Staff Development Team. The first has a media productions section, which develops slide-tape and video-tape programmes. The Staff Development Team has produced training programmes for ENCOR staff, for parents and foster parents and for staff from other mental retardation agencies in Nebraska. All ENCOR staff are trained in behavioural analysis and the use of precision teaching methods - which are central to the individual clients' programmes. In 1977, all ENCOR staff went through a course in the use of case conferences and working in a multi-disciplinary team: it took four weeks for them all to go through the 8-hour programme. ENCOR's commitment to staff training is one of its most impressive aspects. One of the most important consequences is that every member of staff has a common philosophy - normalisation - which means a common purpose in all that they try to do for their clients.

#### Professional Staff

These staff are now organised in a "trans-disciplinary team" which provides psychology, nursing, physiotherapy, speech and occupational therapy to all ENCOR services. Local doctors provide medical care and psychiatric services and advice come from local agencies.

ENCOR's professional staff was also hard hit by the financial cuts. By 1977, apart from the coordinator, one occupational therapist, two physiotherapists, two speech therapists, and two nurses made up the team. Each member, representing the whole team, will reckon to go to four case conferences on clients each month. In addition, the team employs a carpenter, who spends much of his time building individually measured and designed chairs and aids for ENCOR clients.

Before the financial cuts, the team consisted of two occupational therapists, two physiotherapists, a nurse and four psychologists, as well as 14 speech therapists.

### Planning Department

The five members of this relatively new department are responsible for all long-term planning (up to 10 years), in consultation with the staff. Before the department was set up, each Division planned for itself. Staff now seem to have high expectations that the team will help them provide services which are as faithful as possible to the principle of normalisation.

### Administration

Since 1975, ENCOR has been part of the Eastern Nebraska Human Services Agency, which covers mental health and geriatric services as well as those to people with mental handicap. This agency provides central administration and support to ENCOR, including clerical services, finance and purchasing, budgeting, grant-writing and accounting, property management and personnel services.

As an example of some of the work of this division, the 1974/5 budget summary records that during the previous financial year the personnel department was involved in 2,400 interviews of applicants for some 307 posts. It also developed a system of personnel reports, and of management reports which keeps all divisions up to date on their absence and turnover rates and how these relate to the agency total.

Most of these functions are fairly typical of an administration division within an Area Health Authority or a Social Services Department in Britain. However, staff within ENCOR's central administrative services gave the impression of knowing more about mental handicap, of greater commitment to the agency's client-centred goals, and of a greater sense of creative involvement in achieving these goals than do similar staff in this country. Senior administrative staff at ENCOR showed a strong desire to improve its accountability to its local governing body, to the Federal agencies that provide much of the finance for the programmes and to the consumers. They were not locked into a narrow concept of cost accounting, which often seems an end in itself in this country, rather than a small component in a system of personal, programme and agency accountability.

### Budget

Details of ENCOR's 1976/7 budget are in Appendix 3. The total budget for the year was \$5<sup>1/2</sup>m, of which roughly half came from Federal sources. The Residential Division spent some \$2<sup>1/2</sup>m of this total and the Vocational Division some \$1<sup>1/2</sup>m. The average annual expenditure on accommodation per client was \$7,600 (not all clients, of course, were accommodated for a full year).

### Organisational Aspects

Between the conceptualisation of model services and actual developments must come an organisation with clearly defined aims, a simple and flexible structure, and a sound funding base. Any organisation which purports to provide human services must also build in consumer and taxpayer participation to the design, planning and continuing assessment of the services, if it is to ensure real accountability. E.N.C.O.R's organisation was designed to incorporate these principles.

A number of important administrative changes recommended in the State plan had already been embodied in various Acts of the Nebraska Senate, and provided a framework within which six Regional Offices could be established.

Responsibility for ensuring the provision and co-ordination of all services to mentally handicapped people was now vested in a single State Office of Mental Retardation. Matching funds were made available by the State to encourage the establishment of Regional Offices by co-operative action on the part of a number of County Authorities. At the same time the Local County Authorities were relieved of their financial commitment to the State's large institutions.

ENCOR was one such regional office. It had a small governing body which reported to the State Office of Mental Retardation. In 1977, one commissioner (the equivalent of a British local authority councillor!) from each of the five counties served by ENCOR and five advisory members (parents or professional workers) made up the board. It had its own budget, originally made up of about 30% county, 55% Federal and 15% State funds; this ratio had latterly become 10%, 50% and 40%. There was also an advisory committee, made up of three parents and/or concerned citizens from each of the five counties, which advised both the board and the executive director.

In 1977, ENCOR's officers consisted of an executive director, a permanent deputy, and four divisional directors, each responsible for one of the service divisions already described. The director had two direct advisors, one concerned with public education and public relations, the other with planning and evaluation.

An important feature of ENCOR's organisation has been its flexibility. This has shown itself in the location of different service components in the most appropriate division and the creation of a separate division where the need was established. The developmental day centres (special schools), originally part of the family guidance service, subsequently became a division on their own and finally part of a large division of developmental and vocational services. This ensured that programming skills, backed by a psychologist, were available to children and adults and that there was continuity of educational programmes - something which in this country requires special formal and informed coordination between two or more separate departments. A similar readiness to introduce administrative change can be seen in the movement of the behaviour shaping unit into the mainstream of residential services and the subsequent integration of the children in it with less disturbed and difficult ones, in more normal settings. The transfer of the Developmental Maximisation Unit into residential services underlines ENCOR's decision to provide a home-like environment for all children. A similar flexibility is to be seen in the move from centralised control in the residential and family services divisions to an increasingly decentralised organisation. Family support services were originally based at ENCOR's central office. However, as the organisation grew, a number of decentralised area offices, equivalent to English Area Social Services offices, were established, each with their own Field Work Controller.

A combination of decentralisation and transfer of responsibility between divisions is shown in the decision to develop and support all alternative residences from the closest training hostel. This has ensured that services become even more "local" and responsive to client need, able to exploit in full the resources of the local community.

#### Key features

The key features of ENCOR's organisation in terms of decision-making about clients and their families seem to be:

- i . ease of initial access to ENCOR by clients

- ii. clear allocation and specification of responsibility between divisions and between personnel at various levels within a division.
- iii. clear specification of methods of communication between staff and clients.
- iv. the provision of a professional advocate - usually one of ENCOR's social workers - to provide continuity of contact and coordination of care.
- v. the primary consideration given to the wishes of the mentally handicapped person or his or her representatives.
- vi. skilled use of the individual programme plan - a written plan of action, drawn up by an inter-disciplinary team, with clearly specified goals, intermediate steps, methods of achieving these goals and responsibilities. (See Appendix 5).
- vii. instruction of all staff in the policies and procedures of the agency and the availability of detailed manuals on these.
- viii. well developed recording systems.

Potential clients are able to gain information or access to ENCOR's services through the central inquiry office already described. Initial personal contact with the client and his or her family is then made by an intake social worker. It is usually a member of the family guidance division who acts as the key liaison and coordinating worker, offering a personal service and continuity for a client as he or she moves through ENCOR's many programmes. It is the Director of the Family Guidance Division, acting on advice from social workers within that division, who decides about clients' eligibility for services. Decisions about entry into residential services are made at review meetings attended by the social worker, residential care coordinator and the appropriate residential care staff.

Other specialists receive notification of all meetings and have the right to attend. Decisions about moving from one of ENCOR's facilities to another are made at individual programme plan meetings, convened and chaired by the client's own social worker, who is also responsible for record keeping. Programme specialists, like psychologists, doctors and physiotherapists, offer a consulting service, as we have seen above.

#### DETERMINANTS OF SUCCESS

We have already outlined ENCOR's antecedents and explained how Nebraska's government was persuaded both to improve care in the State's institutions and to make a new commitment, backed by administrative and legislative action, to alternative, community-based services. The parents, working from outside the system, with considerable help from informed professionals, also working "outside", had a good plan, with a balanced appeal to values and economics. They also had a good understanding of the power of the media in winning the hearts of elected state officials.

In this section, we try to identify the major features which sustained radical change and influenced the development of such a comprehensive range of high quality services, within such a short time. Why should the system in Eastern Nebraska show such an ability to adapt to changing demands? Why didn't ENCOR go for a conventional range of community-based

services? Why did it set itself such seemingly impossible targets?  
How does it manage to remain client-oriented?

Four independent but related factors seem to have been important:

- the philosophy - which guided the design, evaluation and modification of ENCOR's programmes
- \* the leadership - people within the agency and outside it, with tremendous drive, skill and commitment to mentally handicapped people and their families; these people were able to provide a creative interpretation of the philosophy as well as decisive leadership.
- \* the specialist agency - a model which allowed exclusive focus on mentally handicapped people and their families, encouraged a cohesiveness which is vital in the early stages of a new service and made for easy exploitation of new funding arrangements; and the way in which the agency was organised to allow internal and external accountability, relationship with other agencies and maximum staff support and development
- \* the parents' organisation - its involvement and influence

#### The Philosophy - Normalisation

Since there is widespread misunderstanding of the principle of normalisation in Britain and so a constant risk of simplistic rejection, it may be worth some elaboration.

The most detailed explanation and analysis of normalisation is found in the writing of Wolfensberger'. He defines the principle as "the utilisation of means which are as culturally normative as possible in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible". This deceptively simple principle, together with its major corrolaries, provide a conceptual framework of attitudes, beliefs and values which can be used in a number of important ways. It can be used to sharpen our awareness of other ideologies which have up to now shaped the form and organisation of services for mentally handicapped people. More important, it can be used to re-sensitise us to our own attitudes and behaviour towards mentally handicapped people, and can be used in the design of new services.

"Normalisation" is concerned with our behaviour towards those who we define as mentally handicapped. It is not in itself an empirical statement. However, it is in no way inconsistent with current empirical knowledge, and indeed requires knowledge of prevailing culture, and of ways of maximising the development of personal and social skills in handicapped people if it is to be applied.

The principle is concerned with both process and goals, particular emphasis being given to the process. We are encouraged to give careful thought not only to the development of adaptive behaviours by the handicapped person, but also to how we are to facilitate these behaviours. We are encouraged to make informed choices about the methods and approaches we adopt, to recognise that handicaps exist as much in the eye of the beholder as in the "handicapped person". For these reasons, it is important that mentally handicapped people are presented and interpreted to others in a culturally normative manner - as people with hopes, expectations and abilities, as members of society with a contribution to make rather than as outcasts - and in normative environments which will minimise perceived "differences".

There is a preventative aspect of the principle. In talking of "maintaining" behaviours, Wolfensberger indicates not only that we must



in our programmes support newly established normative behaviour, but also that we must further strengthen normal behaviours in those who might otherwise be classed as handicapped.

Whether we decide to apply the principle of normalisation will depend on values independent of the principle itself. But those who wish to offer abnormal kinds of service should make explicit the value base and the expected benefits of their approach. The onus is upon those who seek to maintain "abnormal" living environments for mentally handicapped people to demonstrate the value of these environments. In the absence of evidence we are bound to argue that we should adopt the principle of normalisation, and use means which are as normative as possible to establish and maintain behaviours and patterns of life for the handicapped person and his family which are as normal as possible.

Wolfensberger suggests that there are two major action dimensions to normalisation. One concerns our interaction with mentally handicapped people, while the other concerns the way in which they are interpreted or presented to others. He also suggests that we can think of application of the principle at three levels - the personal, primary and intermediate social system, and societal.

A SCHEME OF THE EXPRESSION OF THE NORMALISATION PRINCIPLE  
ON THREE LEVELS OF TWO DIMENSIONS OF ACTION

<u>Levels of action</u>	<u>Dimensions of action</u>	
	<u>Interaction</u>	<u>Interpretation</u>
Person	Eliciting, shaping and maintaining normative skills and habits in persons by means of direct physical and social interaction with them.	Presenting, managing addressing, labelling and interpreting individual persons in a manner emphasising their similarities to rather than differences from others.
Primary and intermediate social systems	Eliciting, shaping and maintaining normative skills and habits in persons by working indirectly through their primary and intermediate social systems, such as family, classroom, school, work setting, service agency and neighbourhood.	Shaping, presenting and interpreting intermediate social systems surrounding a person or consisting of target persons so that these systems as well as the persons in them are perceived as culturally normative as possible.
Societal systems	Eliciting, shaping and maintaining normative behaviour in persons by appropriate shaping of large societal social systems and structures such as entire school systems, laws and government.	Shaping cultural values, attitudes, and stereotypes so as to elicit maximal feasible cultural acceptance of differences.

### Normalisation in action

There is little doubt that an explicit commitment to normalisation, and a readiness to explore it in full, is one of the cornerstones of ENCOR's success. The commitment comes from both the agency itself and individual members of staff in their relationships with mentally handicapped people.

The commitment to normalisation influenced the decision to adopt a system of dispersed residential units, schools and workshops rather than a model in which all three are located on a single site. The commitment to the greatest possible physical integration of facilities allowed ENCOR to use existing houses, schools and other property, rather than building new ones. This decision was important: it ensured that units were small and served small social and geographic communities; it also allowed clients to use services available to non-handicapped members of the population.

These initial decisions allowed for an incremental development of the major components in a comprehensive system of services. This had considerable advantages. Experience gained at one stage could be used to modify the next; it was not necessary to employ and train large numbers of staff in a short period of time; it was possible to provide an immediate demonstration of success on a small scale, which could be used in arguments for further resources.

The principle of normalisation did more than influence the original pattern of services. It also helped to ensure that the system was dynamic and set a direction for change. ENCOR wanted to provide the least restrictive, most normative environments to each client and to reach its ambitious targets in the most cost-effective way it could. So it looked more and more to providing a specialised service within more socially integrated settings. Instead of building more homes for short-term relief, ENCOR turned to finding "normal" homes which would provide short-term care. Instead of acquiring more staffed training hostels, it developed more active programmes of support, which allowed families to continue to care

Parents are asked: "What would you need in order to keep your child at home?" rather than being helped to come to terms with that child's removal. They are helped to construct and maintain both a "structure for coping" and a "structure for living", in Michael Bayley's terms<sup>5</sup>. Where this proves impossible or inappropriate, the least restrictive alternatives are sought - adoptive or foster homes. For adults, ENCOR looks towards more independent ways of living. Similar trends towards integration can be seen in its education and work programmes.

Finally, the principle of normalisation has been used as a basis for a check list which can be used to evaluate programmes - Programme Analysis of Service Systems (PASS). This technique has been successful in ENCOR's staff training, in the agency's evaluation of its own services and in evaluation of services by consumer representatives. It is one of the things that has stimulated ENCOR's continuing sensitivity to the needs of clients<sup>6</sup>. (See Appendix 6).

### The Leadership

However sound the philosophy, there must be people who can interpret it and secure the resources to implement services. Omaha had strong leaders among parents and the executive directors of their associations, and among University-based professionals. This leadership was further strengthened by a highly capable Executive Director of ENCOR, who in turn was able to attract a number of very competent Assistant Directors.

The important point is that the personnel model used had to do with the development of particular programmes. Staff were selected for their ability rather than because they had a particular professional qualification. As a new agency, ENCOR was not hamstrung by the narrow professionalism which is so often a feature of long-established bodies. It was therefore able to establish programme structures rather than parallel departmental or professional ones - and to appoint people who could contribute to those programmes, whatever their professional qualifications or lack of them.

E.N.C.O.R's first Executive Director was a young man, under 30 years of age, with a degree in Business Administration. His successor was an even younger woman, aged 26 years, who had originally come to the agency as a volunteer, and had subsequently gained a degree in psychology. Assistant Directors were selected for their commitment to community-based services, and their managerial ability. The head of the Developmental and Vocational Division was a psychologist with wide experience and knowledge of structured teaching programmes which were developed. The Assistant Director, Residential Services was a powerful divergent thinker who realised that flexibility, change and above all progress by clients through various residential settings into the least restrictive environment possible was the only way to combat the high costs and inherent staffing problems of traditional forms of residential care. At all levels within the organisation there was clear evidence of creative conflict, drive and commitment to common goals.

#### The Specialist Agency

The third determinant of success was the decision at State level to charge a single agency with the task of developing the new community-based services through autonomous local offices. This helped ENCOR in a number of ways in its early stages. It made implementation of the detailed plans easier: operational policies could be formulated without protracted negotiations with a number of other agencies and without hindrance from existing professional role structures. New plans could be drawn up rapidly, decisions about priorities established without reference to conflicting claims from other client groups, and application made for funds from previously unexploited Federal Agencies. At personal and inter-personal levels, it was possible to develop a new ideology, a singleness of purpose and a cohesiveness which would have grown much more slowly between a number of people dispersed through generic agencies; there was no other demand on staff's time or exposure to professionals who did not share their optimism, as there would have been if they had been in a generic setting.

Finally, the establishment of a single agency made for the easier specification of short-term and long-term goals, a clearer allocation of responsibility to groups of staff for achieving these goals, and so the possibility of developing internal and public accountability.

It should, however, be emphasised that a single agency model does not in any way guarantee good quality service, accountability or adaptive change and improvement in services. Without the ideological base and skilled leadership already described, even community-based services could have become bureaucratic and static, restrictive to the growth of mentally handicapped people and their families. What made ENCOR unique and ensured its success was its commitment to planned development towards services which are equal or superior in effectiveness to the special or segregated services. ENCOR did not seek to duplicate any existing services which it considered were of a reasonable quality. When it moved clients into integrated schools or work situations, it ensured

specialist support; colleagues in ENCOR in turn provided continuing support for those who went as resource personnel into generic agencies.

#### The Parents' Organisation

At the beginning of our paper, we discussed the major part played by individual parents and their organisations. They had helped to create a climate for radical change; they put their ideas into the plans, lobbied publicly to create interest among elected representatives at State and County level and ensured that the necessary legislation was introduced.

But having achieved this quite remarkable success, the parents did not simply fade out. Their strong and continuing influence both locally and through the Greater Omaha and Nebraska Associations for Retarded Citizens not only contributed to some major service developments, but also ensured ENCOR's continued existence through severe political and economic difficulties. How did the parents exert this influence?

In the first place, they had representation on ENCOR's governing board and on the advisory committee which advised both the board and its executive director. This ensured critical examination of ENCOR's performance and of its plans.

Secondly, small groups were established in each area to visit the local units and to discuss problems with clients, their representatives and staff. On the whole, the constructive criticism offered by parents' groups seems to have been well accepted by staff at ground floor level, both because it was usually well informed and because the staff saw parents as allies in pressing for change at other levels within the organisation.

Equally important, parents and agency shared a common philosophy and a common language. This was well demonstrated when one of us (DT) was able to sit on a training session designed to make parents familiar with PASS. Here were parents learning along with ENCOR staff to use a highly detailed and sophisticated evaluation method, with which they would be able to bring objectivity to their assessment of the quality of service being offered.

Fourthly, the parents' organisation was able to augment the activities of the agency not by attempting to provide revenue-intensive services - they had given this up at an early stage - but by providing an information service to new parents, by offering individual parent to parent support, by organising volunteers and assisting in the development of citizen advocacy programmes.

Finally, the parents maintained an active role as a political pressure group at County and State level. They had helped to promote the Right to Education Bill - which helped ENCOR in its push to get its children from special schools into mainstream education. They had also fought hard to resist budget cuts in 1975. In 1976, they determined that ENCOR's hard-won and successful innovations in community care should not be negated by reactionary professional counter-pressures or by short-term political expediency.

#### Facing problems - money and morale

It is evident to visitors that one important component is missing in ENCOR's service. It cannot claim to provide a comprehensive service until it can accommodate the most severely and multiply-handicapped adults of its regions; this is the one area where it has not yet shown that normalisation works. But this is not because it has failed. It is

because it has not yet had the chance to try. The Adult Multi-handicapped Unit was set up at the beginning of 1976 to do the same for adults that the Developmental Maximisation Unit had already done so successfully for children - to provide assessment, training and placement for those on their way from the State Institution to more normal settings. The adult unit never had more than 2 clients, because in mid-1978, it had to be scrapped for lack of money.

This was one of the most significant casualties of the cuts. As we have seen, these cuts had a drastic effect on services. As a result of them, directly or indirectly, all the executive staff resigned [and were replaced), between 1975 and 1976. In addition, almost all the professional staff were twice threatened with redundancy - they all left and only some have been replaced. Many other staff - particularly advisors in the Family Guidance Division - were made redundant. Morale has clearly suffered. ENCOR fought against the cuts - mobilising public opinion, marching in the streets - and they lost the fight.

The battle was about more than money. The governing board had decided that it should dictate not only the overall cuts, but on which services the axe should fall. For some time before, the Board had been chipping away at the power of the executive staff; when these people were replaced, there was a feeling both within ENCOR and outside it that the new staff were chosen as likely to toe the Board's line, rather than being necessarily the best people for the job. Whether this is true or not, morale is suffering because some members of staff believe it. There is, in addition, a lack of leadership: there was only a "temporary director" between March 1976 and February 1977 and between then and April, no director at all. Staff at lower levels of management felt, in 1977, that they were getting very little support.

Turnover of staff is also - not surprisingly - a problem in the residential division. Although written figures on this turnover were not available, it seems that three years ago, this turnover was nearly 60% per year among full-time staff and 100% among part-time staff. Certainly a large number of residential staff are students or people who have only recently left college. There is also certainly far less turnover among managers and deputy managers of residential clusters.

The drive and initiative of people in any organisation must clearly be affected by financial problems and constant staff changes. Some people in this country have wondered whether ENCOR will be able to keep its initial drive - indeed, it is hard to avoid the impression that some have positively hoped it will not. For pessimists and those who wish to ignore its importance, ENCOR is certainly showing some signs of tiredness. In 1977, some people there felt that the organisation was ossifying - and that those at the top were taking some of its ways of working too much for granted. "Alternative living units", for instance, are now being seen as one particular type of accommodation, rather than a concept designed to make people think about new ways to provide accommodation. ENCOR is at risk of resting on its laurels - which is perhaps hardly surprising, in view of the very large collection of laurels it has.

There is nothing, of course, which dictates that ENCOR should, having pioneered so much, continue to remain in the vanguard. But it is certainly showing signs of determination to do so. The new planning group, set up in April 1977, was mentioned both within the organisation and in the local consumer group, GOARC, as a hopeful sign for the future: there seemed to be a great deal of faith that it would not allow ENCOR to get stuck in a rut. Although the future may not bring much more

money, there are already indications that it will bring improved morale.

#### ENCOR's LESSONS FOR BRITAIN

Since it began, ENCOR has succeeded in developing a wide range of "alternative" community-based services for mentally handicapped people. These services have grown in quantity and quality at a rate which is unprecedented in either Britain or the USA.

The sense of excitement we experienced during our visits, and experience even now, is not easy to convey. As a comprehensive network of services, ENCOR represents a serious challenge to all other programmes for mentally handicapped people of which we have knowledge or direct experience. ENCOR and its staff also challenge at a more personal level. They challenged some of our own more restrictive stereotypes about mentally handicapped people and the form and organisation of services for them.

This is not to say that there are no individual components of British services to compare favourably with ENCOR's programmes - or which may indeed be superior to parts of these. There are work training and further education programmes in adult training centres in this country which compare well with those we visited in Omaha. The "work stations" in industry were similar in conception and implementation to those developed in parts of England and Wales. The quality of the teaching programmes in the ENCOR developmental centres was not superior to that in a number of special schools in this country. The care and training for residents in training residences in Omaha was not necessarily better than that provided in our better children's homes and small adult hostels.

It is often said that comparisons between our own services and those in other countries serve no useful purpose, because of major historical, cultural and administrative differences. There are, of course, important differences in the political structure, in the funding and organisation of various human service agencies, and in the development of professional groups involved in the care of mentally handicapped people. A Federal system of Government has advantages if one wishes to innovate within a particular State. There are established procedures for the introduction of special agencies which can demonstrate a new pattern of services and then be absorbed into existing generic agencies. American parent and consumer groups accept their political role more easily than do comparable groups here; they are able to use the courts in their battles with State Government. Eastern Nebraska clearly has its own differences as well: there is, for instance, more property to let than in this country and, in 1970, a surplus of trained teachers.

However, the concepts, many of the service models and the drive and enthusiasm of ENCOR could and, we believe must, be created in the UK. There is already evidence of a fairly fundamental rethinking of our strategies for developing comprehensive community-based services for mentally handicapped people - and indeed, all developmentally disabled groups. ENCOR's experience can contribute to this reassessment.

Many of the lessons we can learn from ENCOR are evident in the description of what the agency has achieved and the way it has gone about its work. The basic lesson is that real change will only come about if it is the expression of a philosophy which asserts the right and the capability of mentally handicapped people to become part of the society into which they were born. Visitors to ENCOR must be struck by the unashamed, explicit morality of the service. They will be particularly struck if they come from Britain, for our approach tends rather to be cold and empirical.

If we start talking of social and personal values, people become uncomfortable. ENCOR's personnel are not ashamed to talk of, and to work by, these values. They reach an understanding of themselves through their work and they are not ashamed to say so.

This approach does not come haphazardly, ENCOR's explicit philosophy of normalisation is explained to every member of staff. Its staff training, as we have seen, has always been thorough and imaginative. ENCOR staff have always been self-critical and encouraged parent and consumer organisations to be critical of their services as well. They have even, in PASS, provided them with a critical tool. There is surely a second lesson for Britain in these approaches.

As this report makes clear, the philosophical position on which ENCOR and its staff base their work leads to anything but woolly application. A third lesson of the service for us must be that many things are possible if enough sheer hard work goes into the implementation of ideas. There is little which has been random in ENCOR's development of services; in this, it contrasts strongly with the haphazard development of services in this country. The fact that, for instance, Regional Health Authorities, five years after the publication of "Better Services for the Mentally Handicapped", still showed a direction which was "diffuse, variable and uncertain", while planning procedures were still "clearly inadequate to ensure that future developments will lead to a coherent and coordinated pattern of services, geared to the needs of mentally handicapped people", would surely be greeted with amazement in Omaha.<sup>10</sup> While planners and providers of services in Britain indulge in talk of "community-based services" which in some quarters can even include large hospitals, ENCOR is creating a community service. It has not been afraid to lobby hard for what it wants and to ensure that parents and professional workers fight together. There is a lesson in that determination and that unity as well.

This is not to say that ENCOR's approach is dogmatic. One of the most impressive aspects of its record has been its ability to admit that its original ideas were simplistic or over-restrictive. Its development of residential alternatives to the small community home is the most striking example of this; compare and contrast the way in which most authorities in this country seem stuck with the purpose-built hostel, offering up to 24 places. The flexibility of ENCOR, its willingness to throw over conventional professional leadership assumptions, to push further the logic of its own philosophy, must surely be a fifth important lesson for us.

Nor does this mean, as it easily might, that ENCOR has inflated notions of its own contribution to the lives of its clients. It recognised very early on that normalisation demanded that, whenever possible, clients should get the help they need through existing generic patterns of service. As its developing services show, its aim is always to enable the client to get the best service possible, with help from ENCOR staff as necessary, in the most "normal" setting possible. There is a lesson to be learned from this approach in a country which insists on segregated schools, work programmes and residential homes as the major component of services, with all the emphasis on the "difference" of mentally handicapped people that these bring in their wake.

All these lessons should be applied to British services, within the existing structure. The recent introduction of Health Care Planning Teams, which should bring together representatives from all health and local authority services concerned with mentally handicapped people, makes planning a comprehensive service, of the sort that ENCOR provides,

perfectly possible. What we need is a commitment to introducing such a service, through carefully planned and evaluated local initiatives. We need those with local responsibility to study carefully the contribution of ENCOR, to visit its services, and to learn from them.

Finally, we should remember that whatever ENCOR does, it tries to do in the best interests not of the organisation but of the mentally handicapped person it serves. It has seized the concept of individual programme planning as a valuable tool to ensure that the mentally handicapped person is always at the centre of the stage. We are back to the philosophical start: ENCOR believes that mentally handicapped people have the right and the ability to contribute to their society. Perhaps that is the most important lesson of all.

#### R E F E R E N C E S

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- <sup>2</sup> Governor's Citizens' Committee on Mental Retardation 1970. "The Report of the Nebraska Citizens Study Committee on Mental Retardation. Vols. 1 and 2. Lincoln, Nebraska, State Department of Public Institutions 1970.
- <sup>3</sup> Governor's Citizens' Committee on Mental Retardation 1968. "Into the Light". Lincoln, Nebraska, State Department of Public Institutions. 1968.
- <sup>4</sup> Menolascino, F., Clark, R.L. and Wolfensberger, W. 1968. "The Initiation and Development of a Comprehensive, County Wide System of Services for the Mentally Retarded of Douglas County". 2nd Ed. Vol.1. Omaha, Nebraska, Greater Omaha Association for Retarded Children. 1968. "The Initiation and Development of a Comprehensive County Wide System of Services for the Mentally Retarded of Douglas County", 3rd Ed. Vol. 1& 2. Omaha, Nebraska, Greater Omaha Association for Retarded Children. 1970.
- <sup>5</sup> Wolfensberger, W. and Menolascino, F. "Reflections on Recent Mental Retardation Developments in Nebraska 1: A New Plan. "Mental Retardation, 1970, 8 (6), 20-25. (a).
- <sup>6</sup> Wolfensberger, W., and Menolascino, F. "Reflections on Recent Mental Retardation Developments in Nebraska "11: Implementation to Date". Mental Retardation, 1970 8 (6), 26-28 (b).
- <sup>7</sup> Wolfensberger, W., "Normalisation", National Institute on Mental Retardation, Toronto, 1972.
- <sup>8</sup> Bayley, M., "Mental Handicap and Community Care", Routledge and Kegan Paul, 1973.
- <sup>9</sup> Wolfensberger, W., and Glenn L., "PASS 3", Third Edition, National Institute on Mental Retardation, Toronto, 1975.
- <sup>10</sup> Tyne, A., "Plans and Provisions for Mentally Handicapped People", CMH, 1976.



APPENDIX 1

ENCOR SERVICES: 1975/6

Clients served:

Children - In year; 630  
 Using one or more services, 1.7.76; 322

Adults (over 18) In year; 605  
 Using one or more services on 1.7.76; 486.

Clients served, by service

<u>Service</u>	<u>Children*</u>	<u>Adults*</u>	<u>Total*</u>
Residential	131	157	288
Developmental	220	0	220
Guidance	601	601	1,202
Specialized Services	222	250	472
Transportation	396	228	624
Recreation (until November)	162	329	491
Motor Development Services	211	101	312
Vocational	5	312	317

\*Note: Clients were counted in every service that they received throughout the fiscal year.

VOCATIONAL DIVISION

Clients served and staff - 1976

	<u>Clients</u>	<u>% multi-handicapped</u>	<u>Staff (Administrative and line)</u>
Benson ITC	61	23%	18
Fremont ITC	41	29	12
Northeast ITC	35	23	6
South ITC	39	33	10
Bellevue ITC	31	40	8

WORK STATIONS

Lozier's (2) (Manufacturing)	33		2
Holiday Inn (Housekeeping)	6		1
Geisler Pet Products (Packaging)	13		1
Nebraska Methodist Hosp. (Dish washing)	14		1
Univ. of Neb. Med. Centre (Janitorial)	10		1
E. Nebraska Human Service Agency ("")	3		1
<b>ALL WORK STATIONS</b>	<b>79</b>	<b>17%</b>	<b>9</b>

APPENDIX 1 (continued)EDUCATIONAL SERVICES (1976)

	Children		
<u>Coordinated Early Education (CEEP)</u>	62(65)**		
Home Training	7		
Itinerant DMU Services	2		
Cooperative Classrooms	15		
Cooperative Outreach	5		
Integrated pre-schools (regular)	30		
Travelling Resource Services	7		
<u>School Programme</u>			
Fremont School	7		
	Staff		
	Supervisory	Line	Support
Educational Services Admin.	1	0	3***
" " Team	1	0	6
CEEP	2	20	0
Fremont	1****	3	0

\*\* : figures in parentheses include children receiving more than one service.

\*\*\* : support staff serve entire division

\*\*\*\* : supervisor also has teaching responsibilities

RESIDENTIAL DIVISIONWaiting List for ENCOR Residential Services, 1975

The total was substantially unchanged in April 1977. 42 of these people were multi-handicapped; about 20 of the children would need initial placement in DMU or similar unit.

<u>Present Placement</u>	<u>Children</u>	<u>Adults</u>	<u>Total</u>
Beatrice State Home	54	247	301
Community	53	133	186
Lincoln Regional Center	6	38	44*
Hastings Regional Center	7	0	7
Norfolk Regional Center	0	11	11*
Nebraska Penal Complex	0	14	14*
OMR-BSH Placement Study	0	151**	151*
			714

\* : no assessment has been made of the eligibility of these individuals for ENCOR services or the appropriateness of residential services for them

\*\* : 96 of these are in nursing homes and 50 of those are under 65

APPENDIX 1 (continued)Residential Services Provided

	Clients	% multi handicapped	Staff (administrative & line)
<u>Cass/Sarpy Area:</u>			1/2
Bellevue Children's CORE Residen.	4	100%	7
Cass/Sarpy Children's ALUs	5	90	5
Cass/Sarpy Adult CORE	3	0	3
Cass/Sarpy Adult CORE	2	0	5
<u>Dodge/Washington Area:</u>			1
Fremont Children's CORE	5	100	7
Fremont Children's ALUs	8	87	4
Blair Adult CORE	2	50	5
Blair Adult ALUs	9	22	4
Fremont Adult CORE	3	33	4
Fremont Adult ALUs	19	5	9
Blair Adult CORE	6	0	5
Blair Adult ALU	4	25	1
<u>Central/Northwest Area:</u>			1
Hamilton Children's CORE	5	100	6
Hamilton Children's ALUs	7	57	7
Myott Park Children's CORE	2	100	5
Myott Park ALU	2	100	2
Central/Northwest Adult CORE	2	0	4
Central/Northwest Adult ALUs	9	11	2
Central/Northwest Adult CORE	2	50	2
Chicago Adult ALU	3	0	3
Central/Northwest Adult CORE	3	0	3
Central/Northwest Adult ALU	2	50	3
<u>North/Northeast Area:</u>			1
Cuming Children's CORE	5	100	7
Cuming Children's ALUs	12	66	10
Burt Adult CORE	8	25	6
Burt Adult ALUs	10	10	6
Hawthorne Adult CORE	5	40	6
Hawthorne Adult ALUs	5	0	3
North/Northeast Adult ALU	2	0	2
<u>South/Southwest Area:</u>			1/2
South/Southwest Children's CORE	4	50	4
South/Southwest Children's ALU	2	100	1
South/Southwest Children's ALU	5	40	4
Harrison Adult CORE	4	50	3
Harrison Adult ALUs	5	20	3
Harney Adult CORE	8	37	5
Harney Adult ALUs	11	54	4
<u>Specialized Accommodation Area:</u>			2
Crisis Residence	14	57	7
Crisis Homes	3	33	2
DMU (Development Maximation Unit)	16	100	16
<u>Structured Correctional Adminis.</u>			2
Structured Correctional CORE	2	0	6
Structured Correctional CORE	3	33	5
Structured Correctional CORE	2	50	5

N.B: A 'CORE' is a training hostel for a cluster of houses in an area.

An 'ALU' is either a staffed or supervised house ("alternative living unit").

These figures group all clients and staff in all the ALUs in one cluster.

APPENDIX 1 (continued)BREAKDOWN OF ACCOMMODATION AND CLIENTS  
IN ONE AREA (DODGE/WASHINGTON COUNTIES, 1977)24 Houses:

4 Training houses (or 'core' hostel) for a 'cluster' of houses)  
 10 Staffed houses  
 8 Unstaffed houses (distant supervision)  
 2 Foster families ('Home Teachers')

47 Clients served: (40 adults, 7 children)

14 in the 4 Core hostels  
 20 in the 10 Staffed houses  
 11 in the 8 Unstaffed houses  
 2 Children fostered with home teachers

Number of staff: 40

Area Coordinator	1	
Cluster Manager	3	
Assistant Manager	5	
Residential Assistant	19	full time; 4 part time (work in core hostels)
Residential Associate	10	full time; 1 part time (work in staffed houses and provide supervision to clients in unstaffed houses)
Home teachers (foster families)	2	

APPENDIX 2: CLIENTS' HANDICAPS (1976)

TOTAL CLIENTS (active and 'follow along' clients only) = 798

<u>Level of retardation</u>	<u>Total</u>	<u>Age 0-5</u>	<u>6-15</u>	<u>16-20</u>	<u>21+</u>
Borderline retardation*	54	7	9	9	44
Mild retardation	298	42	30	38	188
Moderate retardation	214	28	41	27	118
Severe retardation	143	24	48	26	45
Profound retardation	16	5	6	3	2
Not determined**	<u>58</u>	<u>16</u>	<u>15</u>	<u>10</u>	<u>17</u>
	798	122	149	113	414

\* Includes individuals admitted to ENCOR from Beatrice before 1974, who were not mentally retarded but who needed ENCOR services.

\*\* Includes infants for whom the evaluator has been reluctant to assign a level of retardation; persons who have had injuries with resulting retardation, but who have not recovered sufficiently to test or assign a level of retardation; persons for whom no recent psychological evaluation is available, including clients discharged from Beatrice several years ago and living quite independently; and some persons on 'follow along' status.

Additional Handicaps

	<u>Percentages:</u>	<u>All ages</u>	<u>0-5</u>	<u>6-15</u>	<u>16-20</u>	<u>21+</u>
Convulsive disorders		24.5	34	32	23	20
Hearing impairments or deafness		13.0	20	17	12	12
Visual impairments or blindness		32.0	37	27	29	39
Speech and language impairments		59.6	72	78	65	47
Behaviour disorders		25.0	4	21	32	31
Cerebral palsy or scoliosis, motor impairments		25.0	38	36	22	18
Cannot walk		7.4	16	14	4	3
Physical handicap		9.5	11	19	8	6
Other health impairments		20.3	25	20	19	19
No secondary handicaps		12.03	9	11	12	13

APPENDIX 3: ENCOR's BUDGET, 1976/7

ENCOR's budget for fiscal year 1976-77 is \$5.54 million

Administrative Services***	\$ 975,867	
Residential Services	\$2,233,790	
Educational Services	\$ 599,939	
Guidance Services	\$ 363,954	
Vocational Services	<u>\$1,368,447</u>	
	TOTAL	\$5,541,997 (Approved)

## FUNDING SOURCES:

Funding sources for the 1976-77 budget are:

County	\$ 576,190
State Office of Mental Retardation	\$1,830,133
Title XX (Federal)	\$2,470,725
Other	<u>\$ 664,949</u>
	TOTAL
	\$5,541,997

Local funds -- including county money, private donations, parent payments, volunteer time, and state appropriations -- draw federal dollars through "matching" provisions of Title XX of the Social Security Act.

\*\*\* Includes amount paid by ENCOR to Eastern Nebraska Human Services Agency for administrative services.

**APPENDIX 4: EXTRACT FROM "LESS RESTRICTIVE ALTERNATIVES IN RESIDENTIAL SERVICES" ED SKARNULIS (UNPUBLISHED PAPER)**

At the end of 1973 the costs of operating our group homes were becoming almost prohibitive. The start-up costs including renovation, fire alarm system, hiring and training of staff, etc., were beginning to approach the \$20-30,000 mark.. Our costs of services are used in this paper for demonstration purposes only. Their value for one-on-one comparison with other communities is probably nil. Local labour conditions, salary schedules, inflation, etc., make it impossible to juxtapose ours with yours. The figures are given to illustrate how a flexible system can also be cost-effective and to lend credibility to our arguments. Ratios would probably work just as well. The per-person-per-day cost in our children's residences were running about \$25 and in the adult residences from \$10 to \$15. Because there were no other alternatives for severely or profoundly retarded adults and because the natural parents of many of our children resisted placement of their child in a "developmental home" with another couple, most of the individuals in our group homes stayed there. Movement of people into these residences, both from the state institution and from the community, became impossible. They had become permanent "homes". Staff members who were initially energetic and enthusiastic about providing training and programming for clients lost their enthusiasm after those clients had remained in the residence for four to five years. Children and adults who had made rapid developmental gains after leaving the institution and entering this more normal environment, began to adopt new behaviours, some of them inappropriate, because they were in such close proximity to other mentally retarded persons seven days a week over a long period of time. Contrary to original predictions, our children and adults were not being assimilated into the community, at least not in their immediate neighbourhood. The groups were still too large for such integration. Many parents became apathetic and complacent, and although the children were in their home communities, they were no more willing to take them back to the natural home than if the child had been left at the state institution 140 miles away. In fact, attempts to place some of our children in developmental homes were angrily resisted by a few parents. Even in some of our expensive, specialised units, such as a medical unit for the multiple handicapped child, parents were resistive to any kind of movement, for example to a more normal children's group home. We erred grievously by making all of our residences seven-day training residences. Parents did not take their sons or daughters home on weekends or holidays and staffing patterns became a nightmare. We were compelled to provide coverage around the clock.

We also discovered that our ability to recruit residential employees, the quality of those employees, and the turn-over rate of residential staff were serious problems. During the last six months of 1973, we had a turn-over rate of 100% for part-time employees and about 60% for full-time staff. Salaries were atrocious (\$400 per month for a houseparent couple who were putting in upwards of 80-100 hours per week). The number of staff assigned to residences was below what it should have been. In summary, we had had many of our high hopes about group residences dashed to the ground, we were headed toward substituting a "mini institution" for the depersonalised large institution, and in meeting the needs of one de-valued exploited group (the mentally retarded), we created another de-valued exploited group (residential service staff members). We had "stumbled over the better on the way to the best."

The same rigid patterns, different in kind but not degree, were beginning to develop with our apartments for adults. First, entry requirements were

set up. They included such things as: (1) must have all self-help skills; (2) must be able to use public transportation; (3) must be independently employed; (4) must be capable of independent living; (5) must be able to handle money. In effect, we very neatly excluded any person who happened to be moderately, severely or profoundly retarded or who had not yet developed one or all of those skills.

Terminology began to get us into trouble. One apartment group was asked to leave (on short notice) by the landlord. They were compelled to take what was available in the community, so they found a single-family house which seemed ideal and rented the place. In another instance, we found an apartment complex with two-three bedroom apartments available on the first and second floors. At the time we happened to have a full-time staff member available, so we had her live in the first floor apartment with two severely retarded clients and placed three more capable clients in the second floor apartment. We assigned a relief staff member to work for her. What kind of alternatives were these? Neither group homes nor "apartments".

However, the problems we faced with developmental home expansion were somewhat more serious. After we reached 12 developmental homes, we studied the population that was being served and discovered that almost all of the children were wards of the state. Children whose natural parents were still involved were not being placed in such homes. Although we used many developmental home parents in crisis homes, many more were not willing to make a semi-adoptive type of commitment, and we therefore had to exclude very capable and interested couples. This, in the face of our inability to set up a sufficient number of group residences, and in the face of our knowledge that 70 children from our region remained in state institutions. And the prospects for group residences were not getting better. Across the country we read of the difficulties that agencies were experiencing because of zoning codes, neighbour opposition and the like. Although we had encountered no problems until then, in 1973 we too ran into stiff opposition in one of our communities. The process of getting that one children's residence established drained our administrative staff dry. A couple of county commissioners who make up the Governing Board of E.N.C.O.R. were becoming more and more hesitant to commit their counties to leasing or purchasing for what seemed to be an endless number of physical facilities -- group homes (54 were envisioned by the Douglas County Plan), offices, developmental centres, vocational centres, etc. By the end of 1973, we had 42 buildings in the five county region. Every new lease or purchase became more difficult to "sell" to our Governing Board.

The length of time from locating a residence to opening its doors grew longer and longer. Having received approval for establishment of a residence from our Governing Board and County Commissioners, renovated the house, installed first alarm systems, and licensed the place, the time lag was nine months from start to finish. Obviously, this also caused planning problems in a 12 month fiscal year. The Residential Services Division employees experienced a sense of despair and frustration because parents and counsellors were identifying ever increasing numbers of people who needed the services, and numbers of new group residences were not keeping pace. We had six children's residences, an average of one per year. This meant it would take at least ten years more to bring back the 60-70 children at the institution.



APPENDIX 5: INDIVIDUAL PROGRAM

Extracts from an article by Robert Perske, former executive director of Greater Omaha Association for Retarded citizens.

The movement toward cooperation instead of competition between professional workers has come to a healthy focus in the treatment and care of persons with mental retardation, cerebral palsy and other developmental disabilities. One citadel for such actions is the Joint Commission on Accreditation of Hospitals, Accreditation Council for Facilities for the Mentally Retarded (AC/FMR). A coming together of finances and expertise has been effected by the following: The American Association on Mental Deficiency, The American Academy of Pediatrics, The American Nurses Association, The American Psychiatric Association, The American Psychological Association, The National Association of Private Residential Facilities, The National Association for Retarded Citizens, The United Cerebral Palsy Association. This joint venture has resulted in the development of some rather exciting and provocative standards for residential facilities and community service agencies.

The intriguing thing about these standards is that agencies will have to show evidence of well-coordinated individual program planning for every person to whom the agency is responsible. If they can't produce such client-centered plans "...of intervention and action that is developed and modified at frequent intervals with the participation of all concerned" (AC/FMR definition), they won't make it .

The AC/FMR Standards -- with this hub of individual program planning around which all components must spin -- have become extremely controversial. Some service agencies feel the standards are too tough. They don't want to have any part of them. Other agencies have caught the thrill of this challenge that could lead to an administrative somersault. They're developing new I.P.P. systems, reorganizing agency efforts around them and applying for accreditation. Many don't care whether they receive accreditation or not; they're using the process as a tool to learn as much as they can about concerted care and treatment of individual persons.

The standards are seen by some as an attempt to break with the past and to harness a new future. Some feel they're too much, but almost everyone feels they are right and they are long overdue.

VITAL COMPONENTS IN AN INDIVIDUAL'S PROGRAM PLAN

1. Each individual's optimal development is central. This is the single two-part concern at which all action must be aimed.

- A. There must be a recognition that each human being has his or her own roadmap and rate of growth that is different from everyone else.
- B. All planning efforts must focus on assisting that person's inimitable development so it thrives at its optimal rate.

Of course, this is not a new idea. Helping persons have symbolically placed hand over heart and mouthed in sanctimonious tones that this has been their great goal for years. Then, they go on their way to carry out treatment-by-the herd, where nobody develops as much as he or she could. The awesome thing about functional I.P.P. procedures is that it can send a cutting beam of light that pierces elaborate theories, practices and facades. If a human being isn't being dealt with as an individual, and if there's no evidence of a reasonable developmental climb, it will become remarkably apparent.

2. A client program coordinator is assigned to each individual. This is done at the onset of developing any I.P.P. It is this person (or persons) who harnesses the efforts of all parties who should be concerned with a particular handicapped individual. These could include the following: The client (and/or the family), Specialized assessment persons, Service agency representatives. Direct care persons. Citizen advocates, anyone else who could aid healthy development.

It is this person's (or persons') assignment to coordinate the I.P.P.'s development, plan for assessments, procure and coordinate direct services, disseminate information as well as monitor the person's overall progress.

There's nothing that says this person should be a certain type of professional or paraprofessional. It merely describes a person who is given a distinct responsibility to oversee and monitor a specific program plan process.

3. Planning begins with client (or family) input. The most important words in such a process might sound like this:

"I want to learn to take a bus to Kansas City on my day off."

"The guys at the bakery are always making fun of me."

"I'm trying to make my paycheck last until the next one."

"It would be fun to buy my own clothes."

"Dottie needs to learn restroom signs."

"Sam is getting too big to hug every woman he meets."

"Johnny gets lost as soon as he's a block from home."

"Billy is frightened by the neighbor's dog."

"Sammy can't sit up very long."

Everyone of these statements by a client or a parent speaking on their behalf could point out fruitful objectives for growth. Why? Because these are their human hopes and desires. Too often, helping persons shoehorn clients into written programs they think a person should have. This may be correct, but helping persons are beginning to see the tragedy of planning any program without getting input from the client or family first. The skill of eliciting as much as possible from clients or families before writing so much as one objective has become a fresh, new art.

4. It's an interdisciplinary venture. The day is coming fast when each assessor, therapist, counselor, teacher and helper -- to name a few -- is seeing himself or herself as a team mate working on behalf of one person. They become a part of a larger orchestra playing a symphony of health and growth for a single human being. The multi-disciplinary activity of coming in, doing one's own thing and leaving without being part of a well coordinated fabric of intervention is fading.

5. The plan is based on relevant assessments. Helping professionals seem to possess a diminishing tendency toward being enamored with their own omnipotence and their own brilliant diagnostic deductions.. Written assessments are becoming more humane and considerate of persons, with where they are and what they need. Now comes the possibility where many concerned persons in an interdisciplinary programming group will share assessments. They are more prone to put "handles" on the assessments they make, to make sure all helping persons -- even the parent and advocate -- will understand exactly what's being seen and recommended. They are learning that an assessment's not a relevant assessment until reasonable program plan objectives can come from it.

6. Specific goals and objectives -- long term and short-term -- are stated separately. For years, treatment goals have contained such generalizations as:

"To decrease hyperactivity..."

"To reduce disruptive behaviour..."

"To maximize his positive self-concept..."

Helping persons are beginning to demand objectives that are more specific and detailed. Furthermore, long-term and short-term must be clearly discriminated.

Distant goals are maddening if we don't know what the early objectives should be as we plan a trajectory toward them.

If a portion of an I.P.P. was dedicated to helping a child learn how to dress himself, it might possess the following progressive objectives:

"Bill will pull on his socks without assistance...Bill will put on his shoes, except for lacing and tying them...Bill will put on his shoes including lacing and tying them within five minutes." Such detailed objectives would be applied to every unit of clothing. A long range goal for all actions could well be, "Bill will dress himself, including laced and tied shoes, socks, underwear, zippered and belted pants and button-front shirt without assistance in less than ten minutes."

7. They are time-framed and sequential. Management-by-objectives proponents have proven conclusively that people accomplish more when they work within agreed upon time limits. This is true whether they reach the goal or not. Often, developmentally disabled persons and those working with them give it their best try when they're aware of the time frame in which they have to achieve a skill.

Also, the old days of writing a plan, working it, and then scrapping it for another is beginning to end. A person's developmental journey in life is sequential. Therefore, a person's realistic program plan should have an evolving, changing sequential flow to it.

8. The Plan is written in understandable language (Behavioral Terms). Each discipline has been guilty of developing its own labels and metaphors which can be used for many things. They can be used as helpful communication among their own kind. Or, they can be used defensively -- even reduced to cheap little swearwords.

Let us suppose that an adult client named Joe has become extremely fearful and distrustful of his two roommates. Bill and Sam. It's no longer enough to say that Joe has a bout of paranoia. It is up to the helping persons to come together and attempt to spell out exactly what Joe is doing. Then the interdisciplinary group would skillfully write a series of objectives in behavioral terms that would support Joe's attempt to achieve a fresh series of healthy interactions with Bill and Sam, if that was the agreed upon direction.

9. Each objective is measurable. Interdisciplinary participants -- including the client and family -- have the opportunity to literally measure how far a person has progressed from January 1 until April 1, or January 1 until July 1, etc. With younger children, it may have to do with observable measurements of the number of steps taken, the number of new words learned, the increased periods of focused attention -- to name a few. With older persons who've moved toward more complex behavior it may have to do with increased work production rate, a combination of social graces being used, the mastery of a series of achievements that made it possible to take a bus to town on a day off, meeting some friends, shopping, attending a motion picture, having supper and returning without assistance. In all cases, a person's direction and progress become measurable things.

10. The plan lists specific modes of intervention. This simply means that the I.P.P. spells out exactly what is being done, how it is being accomplished

and how often it is to take place. The modes of intervention are common knowledge to all persons concerned with a particular client.

11. It assigns specific responsibilities. The I.P.P. literally names the persons and the agencies who have been assigned specific responsibilities for specific interventions. Nothing is left to guesswork and assumptions about who might perform certain actions.

12. The effectiveness of interventions is evaluated. Periodically, the specific service actions need to be questioned:

- Is it more than the client can handle?
- Is the person developing or falling back?
- Was the frequency of intervention too sparse?
- Does the tempo need to be stepped up?
- Is the intervention a total flop?
- What modifications need to be made?

It is such functional individual program planning that helps an interdisciplinary team to "fine tune" their interventions so they are right on and allow a person to achieve optimum development.

13. Barriers to achievement are seriously considered. This takes place at the time objectives are written and at anytime they have not been reached. Many a person's developmental climb has been saved because helping persons took time to list hobbles that may have impeded the progress.

In one situation, a non-verbal six-year-old boy with mental retardation began a series of outcries in the developmental center he attended. Special objectives were written as measures to help this little fellow grow out of such behavior. After three months, it was apparent that all interventions were failing. At an evaluation session, all helping persons were encouraged to list any barriers that may have caused the failure. A teacher's aide stated she felt anger for the lad at this point because he wouldn't look her in the eye anymore. Others stated they experienced the same thing. The pediatrician's interest was sparked. He suggested an emergency eye examination. The eye assessment showed that this boy' was suffering the onset of glaucoma. With this frightening loss of vision, his outcries were understandable!

14. Ongoing review and revision are done at least quarterly. An adequate I.P.P. cannot be kept current and functional without some periodic form of review and modification. Also, crisis situations centered around specific interventions should be cause for review as close to the emergency conditions as possible.

15. A functional I.P.P. is a continuous self-correcting process. With many, this planning activity becomes more than the mere recording of plans, interventions and evaluations on paper. It becomes a strong, flexible, constantly changing but fruitful way of helping human beings to achieve what, for them, is life at its best.

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APPENDIX 6: A WALK THROUGH PASS (Programme Analysis of Service Systems)  
(Drawn up by Greater Omaha Association for Retarded Citizens)

A system of helping services is simply no stronger than the systems to monitor its quality. But what to look for - that's the question.

Training as a PASS rater involves a lengthy process. It's well worth it because one's approach to human services will never be quite the same after PASS. The purpose here, though, is to focus on the attitudes and observations imbedded in this evaluation tool. While complex, PASS leads the advocate to ask questions which often boil down to the simple maxim of whether a person would want to be treated in the same way.

•ASK YOURSELF THESE QUESTIONS ABOUT OUR HOSTELS, HOUSES AND SERVICES\*

INTEGRATION - to take part in the mainstream. To be accepted by peers.

Size or Dispersal

1. Are there so many handicapped persons being served that the surrounding community is not able to accept them?
2. Is the number of people served in a residence so large that the people don't go outside for their personal relationships?

Program and Facility Labels

1. Does the sign outside tell that the people inside are "different"?
2. Would the labels produce a negative or hopeless feeling among most people?

Social Opportunities

1. Does the handicapped person interact with non-handicapped persons where he lives? Where he works or goes to school? In his free time? When he shops, attends church, and the like?

AGE APPROPRIATE STRUCTURES - to be valued by others as a true peer.

Facilities, design and decorations

1. Is the facility, the design of the facility and wall decorations appropriate for the age of the persons being served? Are adults living or working in child-like settings?

Possessions

1. Are the possessions owned by the handicapped person appropriate to his age? Does what an adult owns make him appear child-like?
2. Are attempts being made by staff to encourage their clients to own age appropriate possessions?
3. Is there appropriate space where a person lives for the possessions he owns?

Labels and Forms of Address

1. Are handicapped adults addressed as though they were children? Is a child-like nickname used, such as Tommy or Bobby?
2. Are labels such as kid, child, youngster used when referring to a handicapped child? \*
3. Does the staff use a tone of voice with handicapped adults that would be used with children?

Activities and Routines

1. Are handicapped persons engaged in activities that are appropriate for their age? Do adults work during the day? Is a child's school sessions limited to two hours?
2. Are the daily routines of handicapped persons typical and age appropriate? Is an adult given a coffee break - or is it recess? Is a nap scheduled during a child's school day?

Autonomy (self direction) and Rights

1. Are handicapped persons given a chance to make input into decisions regarding their lives? Who makes the decisions in a person's life?
2. Are handicapped persons assisted in becoming independent rather than dependent? Will he need just as much support six months from now?
3. Do handicapped persons exercise more rights as they grow older?
4. Are handicapped persons encouraged to exercise their rights, such as voting or privacy?
5. Are rights removed only when there has been a determination of reduced competency in the area to be limited? Is the restricting of a person's rights used only as a last resort? Are there other alternatives?

Sex Behaviour

1. Do handicapped interact with the opposite sex? Are they given time alone?
2. Are handicapped persons given support to understand their sexual identity? As a life long process, does it begin at an early age?
3. Is counselling available to handicapped adults who may need assistance about dating, marriage, and birth control?

Personal Appearance

1. How typical of his age is a handicapped person's hair style and clothing? Are there subtle mannerisms that make him look different than his peers?

CULTURE APPROPRIATE STRUCTURES - to know and respond to local customs

Labels and Forms of Address

1. Are labels or forms of address used for handicapped persons which are demeaning, devaluing and implying inferiority? Does the form of address show the person to be valued as an equal?
2. Are handicapped persons labelled by their diagnosis, such as "he is an epileptic" or "his is a retardate"?
3. Are courtesy and respect towards handicapped persons lacking when staff talk to them?
4. In his presence, is a handicapped person talked about as a third party? Does the conversation go on as if he were not there?

Personal Appearance

1. Are staff committed to correct physical defects which make a person look different?
2. What is being done to help handicapped persons and bizarre mannerisms such as self-mutilation, extreme destructiveness, and repetitive behaviours? Do these measures work? Is there a persistent and creative attempt to try again?

SPECIALIZATION - to meet the needs of each person at his particular stage of growth.

1. Is the program designed to meet the specific needs of every handicapped person?
2. As needs change, how does the program change?
3. Is a person regressing because he does not fit into the group by reason of his age, ability or behaviour?
4. Is the activity being done in an appropriate setting under the right need?
5. Does the staff have what it takes in skills and attitudes to meet the specific needs?

DEVELOPMENTAL GROWTH - to enable a person to learn at his own pace.

Physical Overprotection

1. Are physical features built into the facility to prevent handicapped persons' movement?
2. How are situations involving risk used to prompt growth?

Social Overprotection

1. Is control so emphasized or challenging opportunities so lacking that an individual's growth is restricted?
2. Are there some rules in the program that non-handicapped people would not tolerate?
3. Are handicapped persons denied new experience because "they are unable to handle them"?

Intensity of Programming

1. Is there a conviction among the staff that handicapped people are growing? Do their records prove growth is taking place?
2. Is the teaching effort organized? Does it push people to their potential?
3. When growth is stalled, where is the responsibility placed - on the person's handicap or the staff's lack of creativity?

QUALITY OF SETTING - to create an atmosphere where a person feels comfortable and accepted.

Physical Comfort

1. Is the furniture and physical environment comfortable?
2. Is the temperature controlled? Is it quiet? Do the people like the food?
3. If a home, does it have a "lived-in" quality?
4. "Would I feel comfortable if I worked or lived in this place"?

Environmental Beauty

1. Has attention been paid to the appearance of the surroundings? Do the efforts show good taste? What about details?
2. "Is this place pleasing enough to have my family live there?"

Individualization

1. What evidence is there that people are encouraged to express themselves in their own way?
2. Is there a place where a person can be alone?
3. Do people usually do things as a group?
4. Do the individualized program plans reflect the differences in people?
5. Is it evident that staff appreciate individuals as having their own rich personality?

Interactions

1. What interaction is going on between clients, staff and the public? Is it warm, or cold and distant?
2. Are there individual friends among staff and clients? Are people listened to?
3. Who seems left out?
4. "Would I be happy here"?